

**Executive Summary**

*"Communities of color suffer disproportionately from diabetes, heart disease, HIV/AIDS, cancer, stroke and infant mortality. Eliminating these and other health disparities is a priority of HHS."*

*— DHHS Secretary Tommy Thompson<sup>1</sup>*

*"We need to focus on the uninsured and those who suffer from health care disparities that we so inadequately addressed in the past."*

*— Sen. Bill Frist (R-Tenn.), Senate majority leader on his priorities for the 108th Congress*

Inequalities in health care that affect some racial, ethnic, socioeconomic, and geographical subpopulations in the United States ultimately affect every American. From a societal perspective, we aspire to equality of opportunities for all our citizens. Persistent disparities in health care are inconsistent with our American values.

Demographic trends indicate that the number of Americans who are vulnerable to suffering the effects of health care disparities will rise over the next half century. Current data show that some ethnic minorities, as well as low-income families of whatever race or ethnicity, tend to be in poorer health than other Americans. Gaps in income between the richest and poorest households in America are widening. Also, some racial and ethnic minorities are growing at a much more rapid pace than the majority white population. Nearly 1 in 2 Americans will be a member of a racial or ethnic minority—i.e., black, Hispanic, Asian, or American Indian—by the year 2050.<sup>2</sup> Clearly, these trends pose a daunting challenge for policymakers and the health care system.

This historic report, the first annual report on healthcare disparities, is intended to provide a balanced summary of the state of disparities in the United States. This report will demonstrate that disparities exist for many Americans and improvement is possible. Rather than provide a series of snapshots of disparities from individual research studies, this report provides a comprehensive view of the scope and characteristics of differences in health care quality and access associated with patient race, ethnicity, income, education, and place of residence. To date, no report has provided extensive cross-group comparisons that could provide a national roadmap to focused efforts to reduce disparities.

### **What Are "Health Care Disparities"?**

The word "disparity" can be defined as "the condition or fact of being unequal, as in age, rank, or degree." Synonyms for disparity include *inequality*, *unlikeness*, *disproportion*, and *difference*. While disparity in health care has been closely associated with equity, there are several potential reasons for the differences observed at the individual level. For example, a patient may receive fewer medications because of differences in

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underlying disease processes, individual choice, systemic barriers to obtaining needed medications, or some combination of these reasons. When we observe differences in health care for different populations, it may not be possible to clarify causal pathways directly. The purpose of this report is to describe differences in quality of and access to health care to help identify disparities in health outcomes that may be responsive to improvements in health care.

Disparities are most easily identified when there is a clear reference point for what is appropriate and reasonable to expect. While there may be uncertainty regarding many aspects of clinical care, the quality measures presented here have been developed around health care interventions for which there is sound scientific evidence of effectiveness and for which there is a professional consensus and expectation that these services would be provided to all patients. Even after consideration of variation in patients' medical conditions and severity of illness, there should be little deviation from specific quality measures by population.

Access to health care is a prerequisite to obtaining quality care. However, dimensions of access vary in predicting an individual's likelihood of receiving care that has been shown to improve health outcomes. For use of services, patient-reported experience of care, and structural issues such as transportation, there is limited scientific consensus regarding which measures are most responsive to system improvements. In addition, the most important factors may not be consistent across communities and populations.

This report presents a broad array of differences related to access, use, and patient experience of care by racial, ethnic, socioeconomic, and geographic groups, based on valid measures. Many of the differences presented here are large and worrisome; indeed, some will argue, quite reasonably, that they constitute evidence of disparity, irrespective of a clear relationship to health outcomes. Further evaluation of these data should prove helpful in assessing current efforts to address important disparities in access to care.

At this juncture, it may be useful to comment briefly on the complexity of the task. First, as noted above, many factors may lead to differences in health care, especially with respect to aggregate measures of use. These include different underlying rates of illness due to genetic predisposition, local environmental conditions, or lifestyle choices. There are differences in the care-seeking behavior of patients, which vary due to differing cultural beliefs, linguistic barriers, degree of trust of health care providers, or variations in the predisposition to seek timely care. In addition, the availability of care is dependent upon such factors as the ability to pay for care (directly or through insurance coverage), the location, management and delivery of health care services, clinical uncertainty, and health care practitioner beliefs, among others.

Second, there may be differing perspectives regarding the appropriate division of responsibility between the individual, the public sector, and the private sector. Third, to the extent that defining a difference establishes it as a priority for action, it is not clear that reliance upon a consistent numerical threshold is appropriate. For some measures

reported here, a small differential could be critical; for others, a differential may not be critical unless it is very large. It will be important to take into account the impact on patients of the differential.

Last, how the patient characteristics assessed in this report—race, ethnicity, income, education, place of residence, age, and others—affect quality of and access to health care are both independent and additive. This first National Healthcare Disparities Report presents descriptive information for each but does not assess which characteristics are most important for improving health care.

### **Why a National Healthcare Disparities Report?**

Public Law 106-129, the Healthcare Research and Quality Act of 1999, directed the Agency for Healthcare Research and Quality (AHRQ) to develop two annual reports: a National Healthcare Quality Report (NHQR) and this National Healthcare Disparity Report (NHDR). The directive for this report, now contained in section 903(a)(6) of the Public Health Service Act, requires that this annual report tracks “prevailing disparities in health care delivery as they relate to racial factors and socioeconomic factors in priority populations.”<sup>3</sup>

With guidance from the Institute of Medicine, AHRQ developed a common conceptual framework for both reports and, in fact, a focus on quality is at the heart of both reports. As the IOM noted in its report, *Guidance for the National Healthcare Disparities Report*, the “plan to make health care quality a major focus of this report...is appropriate since disparities often represent an ‘inequality in quality.’”<sup>4</sup> The conceptual framework for the NHQR focuses on safety, effectiveness, patient centeredness, and timeliness, with equity as a cross-cutting dimension. Equity, as envisioned by the IOM, is “the provision of health care of equal quality based solely on need and clinical factors.” The NHDR provides a full and comprehensive expansion of the equity dimension. Therefore, these highly linked reports are being released simultaneously and readers are urged to review both reports together to develop a more comprehensive snapshot of the performance of our health care system, its strengths, and areas that should serve as a focal point for future improvement. The performance measures underlying the two reports will be used to monitor the Nation’s progress toward improved health care delivery.

This first NHDR provides a national overview of racial, ethnic, and socioeconomic disparities in health care in the general U.S. population and among “priority populations” to contribute to the public dialogue on how to improve health care delivery for all Americans. These “priority populations, are defined in AHRQ’s authorizing statute (section 901 (c) of the Public Health Service Act) as encompassing both specific population groups as well as geographically-defined groups. In accordance with these guidelines, the NHDR includes data and analysis on the following: low-income groups; racial and ethnic minority groups; women; children; the elderly; individuals with special health care needs, the disabled, people in need of long-term care, people requiring end-of-

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life care, and place of residence (e.g., rural communities). Although other demographic groups may also suffer from health care disparities, they are beyond the scope of this report.

It is important to note that this report is unique in providing a systematic overview of differences in health care for both racial and ethnic groups as well as by socioeconomic status. This is the first comprehensive look at differences by socioeconomic groups. Although not designed to measure the progress of any one program or policy, the data and analyses presented in the report are intended to provide a convenient and comprehensive source of information spanning a broad range of health care disparity issues.<sup>i</sup>

### **Objectives of the First Report**

A vital step in the effort to eliminate health care disparities is the systematic collection and analysis of health care data. This will help policymakers and researchers discern the areas of greatest need, monitor trends over time, and identify successful programs for addressing those needs. This first NHDR builds on and seeks to complement existing work in the area of disparities, notably *Healthy People 2010* and IOM's seminal 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Yet those efforts differ from the NHDR in substantive ways.

The elimination of disparities in health is a goal of *Healthy People 2010*.<sup>5</sup> In contrast, the NHDR focuses on disparities in health care, rather than disparities in health. While conceptually different, the two efforts are integrally related. Disparities in health care can only be interpreted within the context of disparities in health. Disparities in health help identify critical disparities in health care with which they are associated. Eliminating disparities in health care is a logical method for eliminating associated disparities in health.

*Unequal Treatment* extensively documents health care disparities in the United States by race and ethnicity.<sup>6</sup> The IOM's examination finds that disparities in health care are substantial, even after accounting for characteristics typically associated with disparities, such as health insurance coverage and income. But while *Unequal Treatment* demonstrates definitively that racial and ethnic disparities in health care exist, it does not measure the magnitude of the problem from a national perspective. The report also does not address disparities in access to health care or disparities related to socioeconomic position.

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<sup>i</sup> "We need an annual report to measure whether we are making progress in ending racial disparities in health care and improving the quality of life for all Americans," said U.S. Representative Danny K. Davis (D-IL) when introducing the amendment calling for the NHDR. He added: "This amendment is designed to try and make sure that we have adequate and accurate information on which to base policy and budgetary decisions."

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In contrast, the NHDR examines national disparities in both the ability of Americans to access health care and in the quality of health care. It includes an analysis of disparities related to socioeconomic position as well as to race and ethnicity, and attempts to capture the relationship between race/ethnicity and socioeconomic position. The report provides baseline data from which we may be able to measure the effect of national initiatives to reduce disparities.

**Key Findings**

The NHDR provides seven key findings to policymakers, clinicians, health system administrators, and community leaders who seek to use this information to improve health care services for all populations:

- 1) **Inequality in quality exists**
- 2) **Disparities come at a personal and societal price**
- 3) **Differential access may lead to disparities in quality**
- 4) **Opportunities to provide preventive care are frequently missed**
- 5) **Knowledge of why disparities exist is limited**
- 6) **Improvement is possible**
- 7) **Data limitations hinder targeted improvement efforts**

**Inequality in quality exists**

This report presents the most comprehensive national picture confirms that there is significant inequality in quality in the United States. While selected research studies have documented disparities in healthcare services, these examinations were often limited to specific populations with specific conditions. By using nationally available data sets, a national view on healthcare disparities is provided.

This first report clearly demonstrates that racial, ethnic, and socioeconomic disparities are national problems that affect health care at all points in the process, at all sites of care, and for all medical conditions--in fact, disparities are pervasive in our health care system. Our conclusions bring us closer to understanding why, where, and how disparities occur--essential knowledge for devising and targeting programs to eliminate these inequities.

While disparities in health care potentially affect all Americans and individuals from of any group, they are not uniformly distributed across populations. We are only beginning to understand the magnitude of differential burden of illness in populations with special health care needs, such as minority children and poor patients with disabling chronic illnesses. Geography can play an important mitigating role in healthcare disparities. Remote rural populations, for example, are clearly at risk for having worse access and receiving poorer quality care.

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Examples from the NHDR:

- Minorities are more likely to be diagnosed with late-stage breast cancer and colorectal cancer compared with whites.
- Patients of lower socioeconomic position are less likely to receive recommended diabetic services and more likely to be hospitalized for diabetes and its complications.
- When hospitalized for acute myocardial infarction, Hispanics are less likely to receive optimal care.
- Many racial and ethnic minorities and persons of lower socioeconomic position are more likely to die from HIV. Minorities also account for a disproportionate share of new AIDS cases.
- The use of physical restraints in nursing homes is higher among Hispanics and Asian/Pacific Islanders compared with non-Hispanic whites.
- Blacks and poorer patients have higher rates of avoidable admissions.

### **Disparities come at a personal and societal price**

Health care disparities are costly. Poorly managed care or missed diagnoses result in expensive and avoidable complications. As discussed in *Unequal Treatment*: “to the extent that minority beneficiaries of publicly funded health programs are less likely to receive high quality care, these beneficiaries—as well as the taxpayers that support public health care programs—may face higher future health care costs.”<sup>ii</sup> The personal cost of disparities can lead to significant morbidity, disability, and lost productivity at the individual level. At the societal level, distal costs follow from proximal opportunities that were missed to intervene and reduce burden of illness. For example, end-stage renal disease may result from longstanding poorly controlled diabetes. The highly morbid and highly costly condition could potentially be avoided with access to indicated services and effective management of diabetes.

Examples from the NHDR:

- Without screening, cancers may not be detected until they grow large or metastasize to distant sites and cause symptoms. Such late stage cancers are usually associated with more limited treatment options and poorer survival. Minorities and persons of lower socioeconomic status are less likely to receive cancer screening services and more likely to have late stage cancer when the disease is diagnosed.
- Persons with diabetes of lower socioeconomic position are less likely to receive recommended diabetic services and more likely to be hospitalized for diabetes and its complications.
- Many racial and ethnic minorities and persons of lower socioeconomic position are less likely to receive recommended immunizations for influenza and pneumococcus. Once hospitalized, some ethnic and racial minorities, as well as lower income patients, suffer worse quality of care for pneumonia. These differential rates of

vaccination and hospitalization present opportunities for provider-based and community-based interventions to reduce disparities.

### **Differential access may lead to disparities in quality**

Access to healthcare is an important prerequisite to obtaining quality care. Some access barriers, whether perceived or actual, can result in adverse health outcomes. Patients may perceive barriers to delay seeking needed care, resulting in presentation of illness at a later, less treatable stage of illness. For example, a usual source of care can serve as a navigator to the healthcare system and an advocate to obtain needed evidence-based preventive and health care services. Of the major measures of access, the lack of health insurance has significant consequences. Avoidable hospitalizations are a good example of the link between access and disparities in quality of care. These hospitalizations may reflect, in part, the adequacy of primary care. When health care needs are not met by the primary health care system, rates of avoidable admissions may rise. In contrast, perceived problems with specialty referral do not have clear clinical consequences.

Examples from the NHDR:

- Many racial and ethnic minorities and individuals of lower socioeconomic status are less likely to have a usual source of care.
- Hispanics and people of lower socioeconomic status are more likely to report unmet health care needs
- While most of the population has health insurance, racial and ethnic minorities are less likely to report health insurance compared with whites. Lower income persons are also less likely to report insurance compared with higher income persons.
- Higher rates of avoidable admissions by blacks and lower socioeconomic position persons may be explained, in part, by lower receipt of routine care by these populations:

### **Opportunities to provide preventive care are frequently missed**

Our healthcare system continues to emphasize care that occurs after an illness occurs, rather than preventive services that could potentially prevent the illness or reduce the burden of disease. While the NHQR documents that this is a pervasive issue for all Americans, there are significant disparities in the use of evidence-based preventive services for certain populations. For example, while smoking remains the single most preventable cause of mortality, rates of smoking cessation counseling during hospitalization are only 40 percent. For blacks, this rate of smoking cessation counseling is only 29 %. Given the significant impact on morbidity, mortality, outcomes, and costs of care, efforts to target preventive services to populations most at risk would be a critical aspect of an improvement strategy to decrease disparities.

Examples of missed opportunities for preventive services from the NHDR:

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- Blacks and persons of lower socioeconomic status tend to have higher rates of death from cancer. While rates of cancer death may reflect a variety of factors not associated with health care such as genetic disposition, diet, and lifestyle, screening and early treatment of cancers can lead to reductions in mortality.
- Many racial and ethnic minorities and persons of lower socioeconomic position are less likely to receive screening and treatment for cardiac risk factors. The combination of lower screening and effective treatment of risk factors, such as smoking among the uninsured, lend themselves to quality improvement initiatives that can potentially reduce heart disease disparities among populations at risk.
- Many racial and ethnic minorities and persons of lower socioeconomic position are less likely to receive childhood immunizations.
- Many racial and ethnic minorities and individuals of lower socioeconomic status are less likely to receive recommended immunizations for influenza and pneumococcal disease.

### **Knowledge of why disparities exist is limited**

There are complicated interrelationships between race, ethnicity, and socioeconomic status that may result in healthcare disparities. While we may have sufficient data about racial disparities by race and ethnicity, it is difficult to tease out the individual contributions of race, income or education to these differences. For example, we found significantly lower rates of smoking cessation offered to minority patients. However, we cannot determine how much these differences are affected by different levels of patient income, education, or types of insurance. While the relationships between these factors may seem theoretical, a better understanding of the underlying factors that result in disparities could better target improvement efforts aimed at reducing disparities. Further research may help to sort out these issues for future reports.

The report cannot tell us what factors are causally related to healthcare disparities, though it does identify factors that may be related to disparities.

Examples from the NHDR include:

- Many racial and ethnic groups, as well as poor and less educated patients, are more likely to have report poor communication with their physicians.
- Many racial and ethnic minorities and poor patients report more problems with some aspects of the patient-provider relationships.
- Many racial and ethnic minorities and lower income patients report more difficult patient-provider relationships.
- Asians, Hispanics, and those of lower socioeconomic status have greater difficulty accessing health care information, including information on prescription drugs.



### Improvement is possible

While the report offers a sobering view of healthcare disparities, there are some positive findings that suggest that targeted improvement efforts could significantly reduce healthcare disparities. There are some notable exceptions that demonstrate *what is possible*.

- While blacks and poor patients are more likely to present with later stage cancers with higher death rates, black women have higher screening rates for cervical cancer and no evidence of later stage cervical cancer presentation. While it would not be possible to demonstrate a causal link, the significant investment in community-based cancer screening and outreach programs for cervical cancer may be responsible for the lack of disparity.
- Quality improvement efforts have resulted in demonstrable reductions in black-white differences in hemodialysis. A targeted intervention within a quality improvement culture may offer important lessons in disparity reduction.
- Black patients are more likely to receive blood pressure monitoring without any disparity in blood pressure management. A greater perceived risk for significant cardiovascular disease among blacks may result in appropriately increased screening rates and treatment for risk factors. Directed public education campaigns about cardiac risk factors and the importance of an activated patient may play an important role in the lower observed rate of cardiac disparities among blacks.

When detailed data are available at the most actionable level, such as population subgroups, the efficiency of quality improvement efforts can be enhanced. For example, the subpopulation data from the California Health Interview Survey (CHIS) would allow more targeted prevention efforts directed at Asians over age 50 in need of colorectal cancer screening. The information on language spoken at home provides a far more precise target population – Asians who do not speak English were 20% less likely to undergo colorectal cancer screening than their English-speaking Asian counterparts. The disparities report can also serve to identify the best “performers,” learn from their experiences and disseminate the lessons learned to other communities. Community-based participatory research has numerous examples of communities working to improve quality overall, while reducing healthcare disparities for vulnerable populations.

### Data limitations hinder targeted improvement efforts

Our ability to assess the current state of disparities in the United States is limited by the availability of data. There are significant holes in current data collection efforts to monitor our progress towards the elimination of health care disparities. The lack of sufficient sample size for each population can result in an inability to find differences that exist in healthcare access and quality across populations. This inability to “drill down”

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also limits our ability to provide actionable data at the State and local levels that could drive improvement efforts. The lack of a national consensus about the value and importance of race, ethnicity and socioeconomic data results in our inability to set baseline measurements for important segments of the populations. For example, while there may be concerns about the quality of healthcare services provided to Native Americans in rural areas, we cannot address these issues adequately due to limitations in available data. Our ability to identify disparities for certain subgroups, such as Hispanic or Asian sub-populations, is also very limited by available national data.

Our first report on the current state of healthcare disparities in the nation has relied heavily on federal data collection sources. However, it is clear that successful improvement efforts often occur at State and local levels. The National Healthcare Disparities Report should help to provide the impetus and tools for public and private entities that are interested in measuring and monitoring progress to eliminate disparities. While beyond the scope of this first annual report, future reports should also help to communicate successful interventions that may reduce the burden of healthcare disparities in our nation.

The report also raises important questions regarding public reporting of data by race, ethnicity, and socioeconomic status. For example, should national data collection efforts include stratification by race, ethnicity, income and education? Should aggregation for public reporting be required at certain levels, such as local or regional? The NHDR may also prompt questions about fields for race and ethnicity as it relates to the Health Insurance Portability Accountability Act (HIPAA) and privacy concerns.

Finally, though existing national data are useful to address many disparities, there are significant gaps. While improved data would help measure disparities, the field would also benefit from more robust measures that would improve our understanding of the underlying mechanisms and causal paths that result in disparities.

### **Looking towards the future:**

Future reports will reflect our evolving understanding of disparities in access, use, and patient experience of care. These reports will go beyond measures of health care disparities to probe the underlying causes of the differences. Race and ethnicity are associated with various disparities in health care, but the root causes are likely multifactorial and complex. Identifying them and understanding their dynamics is key to designing effective interventions.

## References

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- <sup>2</sup> U.S. Bureau of the Census. 2000. <http://www.census.gov> Accessed March 15, 2001.
- <sup>3</sup> Institute of Medicine, Committee on the National Quality Report on Health Care Delivery. *Envisioning the National Healthcare Quality Report*. 2001. Hurtado, Margarita P., Swift, Elaine K., Corrigan, Janet M., eds. Washington, DC. National Academies Press.
- <sup>4</sup> Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. (2003) National Academies Press.
- <sup>5</sup> U.S. Department of Health and Human Services, *Healthy People*, pp. 11-16.
- <sup>6</sup> Institute of Medicine, *Unequal Treatment*, Chapter 2, The healthcare environment and its relation to disparities (pp. 29-80); Chapter 3, Assessing potential sources of racial and ethnic disparities in care: Patient- and system-level factors (pp. 125-59), Chapter 4, Assessing potential sources of racial and ethnic disparities in care in the clinical encounter (pp. 160-79).